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Editorial

Evaluating rehabilitation - an ongoing challenge

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Research on the effectiveness of rehabilitation interventions is crucial for people with multiple sclerosis (MS), their caregivers, treatment providers and policy makers. Whilst there has been a steady increase in rehabilitation research activity over the past decade, studies have tended to focus on the evaluation of single interventions, such as supervised exercise programmes, and even here there are challenges¹. In comparison few studies have evaluated the more complex packages, such as multi-disciplinary inpatient rehabilitation. Further, as is typical across the rehabilitation arena, many of the studies undertaken have been pilot or feasibility studies which have not moved onto a definitive trial². As a consequence, practice guidelines have been unable to make specific recommendations about the effectiveness of multi-disciplinary rehabilitation, with regard, for example, to MS subtypes, stages of disability or model of service delivery^{3,4}. The recurring conclusion of systematic reviews, guidelines^{3,4} and commentaries⁵ is that there is a need for well-designed trials of rehabilitation therapies with adequate sample sizes and appropriate outcome measures, powered to measure change, over both the short and longer term. The randomised controlled trial of multi-disciplinary inpatient rehabilitation,

reported by Boesen et al. in this issue, addresses this call; it is large (n = 427), covers an important domain (quality of life) and follows up the outcomes at six months. The authors describe this article as being the first in a series on the study, reporting results of a broad range of secondary measures (including costs) in future publications. In doing so, this study provides an important contribution to the rehabilitation evidence base.

Multi-disciplinary rehabilitation is highly complex, involving multiple processes, outcomes and stakeholders. A longstanding tenet is that the content of rehabilitation programmes should be individualised and based on an assessment of the patient's unique needs, which can vary widely both in terms of the presenting difficulties and the underlying contributory impairments. This is in conflict with the desire for standardisation of interventions within randomised controlled studies. A further consideration is the variability of the context (both physical and cultural) within which the intervention is delivered. The literature demonstrates a shared conceptual and practical framework to rehabilitation practice, based on a model of comprehensive care which extends beyond symptomatic treatment and emphasises optimising quality of life. However, no two rehabilitation centres appear to practice or deliver care in an identical way. The structure and funding mechanisms of a country's health care system appears to have a major influence on the model of rehabilitation care provided. For example, in some countries such as those described in this Danish study, large highly specialised MS centres exist, whilst for others rehabilitation is predominately delivered within the community setting by non-MS specialists, or barely at all. A survey undertaken by the International Federation of MS Societies highlighted that of the 52 countries surveyed, only 36 reported the presence of hospital based multi-disciplinary teams⁶. Heterogeneity of patient, intervention and centre characteristics is therefore a reality that researchers need to contend with, even within the relatively controlled context of a randomised controlled trial.

Hence the importance of specifically describing characteristics of participants (e.g. MS type, co-morbidities, changes in pharmacological management), the intervention (content, dose and frequency) and context (staff and setting). This level of detail also enables comparison between studies and meta-analyses, if needed. The TiDiER Guidelines⁷ offer an excellent format for helping to achieve this. While somewhat demanding to provide, this information enables readers to make informed judgements about how transferrable the study results are to their own context. The supplementary material provided by Boesen et al. is welcomed as it goes some way to providing this level of detail.

It has long been argued that the selection process for those admitted to inpatient rehabilitation is critical to its efficacy⁸. Although investigations regarding selection process have been made in other neurological conditions such as stroke, this is not yet the case for MS inpatient rehabilitation. This is important since notable differences exist in this selection process, both within and between different countries. In some units, people with MS are offered inpatient treatment on an annual basis, whereas in others patients are selectively admitted according to current need. A description of the referral criteria is not provided within this article, highlighting an aspect which could be addressed in future studies. It is acknowledged that the huge variation between patients, together with the multiplicity of symptoms and the way they interact, is likely to mean that clinical judgement will always play a major role in the selection process. However, key to enabling better targeting of resources is enhancing our knowledge, based on empirical evidence, regarding how, for whom, and in what circumstances rehabilitation works best.

In order to move multi-disciplinary MS inpatient rehabilitation research further forwards it is now the time to ask specific questions beyond its general efficacy. We not only need to

know whether people benefit from a particular rehabilitation approach, but why. This is likely to come from a combination and integration of the most appropriate methods and a better understanding of underlying mechanisms. Just as people with MS benefit from joined-up thinking in terms of the delivery of their care, so too will MS researchers benefit from thinking about these complicated issues in an intelligent way that is informed by changing knowledge at the cellular level of pathology and disease processes, the individual level of experience, recovery and adaptation, and the social level of context. So while recognising that methodological challenges remain, it is hoped that a steady accumulation of evidence, with contributions such as this study by Boesen et al., will help answer the questions posed to enable better outcomes for people living with MS.

REFERENCES

1. Motl RW, Sandroff BM, Kwakkel G, Dalgas U, Feinstein A, Heesen C, Feys P, Thompson AJ. Exercise in patients with multiple sclerosis. *Lancet Neurol*. 2017; 16(10):848-56.
2. Kaur N, Figueiredo S, Bouchard V, Moriello C, Mayo N. Where have all the pilot studies gone? A follow-up on 30 years of pilot studies in Clinical Rehabilitation. *Clinical Rehabilitation* 2017; 31(9):1238-48.
3. Haselkorn JK, Hughes C, Rae-Grant A, Henson LJ, Bever CT, Lo AC, et al. Summary of comprehensive systematic review: Rehabilitation in multiple sclerosis: Report of the Guideline Development, Dissemination, and Implementation Subcommittee of the American Academy of Neurology. *Neurology* 2015; 85(21): 1896-903.
4. Perry M, Swain S, Kemmis-Betty S, Cooper P, Guideline Development Group of the National Institute for Health Care. Multiple sclerosis: summary of NICE guidance. *BMJ*. 2014; Oct 8;349:g5701. doi: 10.1136/bmj.g5701

5. Feinstein A, Freeman J, Lo AC. Treatment of progressive multiple sclerosis: what works, what does not, and what is needed. *Lancet Neurol*. 2015;14(2):194-207.
6. Browne P, Chandraratna D, Angood C, Tremlett H, Baker C, Taylor BV, et al. Atlas of Multiple Sclerosis 2013: A growing global problem with widespread inequity. *Neurology*. 2014;83(11):1022-4.
7. Hoffmann TC, Glasziou PP, Boutron I, Milne R, Perera R, Moher D, et al. Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. *BMJ*. 2014;348:g1687. doi: 10.1136/bmj.g1687.
8. Freeman JA and Thompson AJ. Is inpatient rehabilitation effective in multiple sclerosis? In *MS: Clinical Challenges and Controversies*, edited by Thompson AJ, Polman CO and Hohlfeld. London: Martin Dunitz Publishers, 1997.

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